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“You helped me keep my head above water”—experience of bereavement research after loss of a loved one in the ICU: insights from the ARREVE study

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Abstract

Purpose: Bereavement research has helped to improve end-of-life practices in the ICU. However, few studies have explored bereaved relatives experience of research participation in this context. We aimed to explore the experience of bereaved relatives' participation in the ARREVE study which included three telephone follow-up calls to complete several quantitative tools.

Methods: Volunteer relatives who participated in the 12-month follow-up call completed a questionnaire about research participation that included ten open-ended questions so that respondents could use their own words and thoughts. These open-ended questions were analyzed using qualitative analysis that examines themes within the data.

Results: 175/311 relatives completed the questionnaire. Three themes were derived from the thematic analysis: (1) struggling: reactivation of emotional distress associated with the ICU experience and the loss is frequent, specifically during the 1st follow-up call. (2) Resilience: as time goes by, research participation becomes increasingly positive. The calls are a help both in giving meaning to the relatives' experience and in accepting the loss. (3) Recognition: research calls can compensate for the absence of support during bereavement.

Conclusion: Although some emotional difficulties must be acknowledged, bereavement research is overall associated with benefits, by facilitating emotional adjustments, meaning-making and resilience. Lack of support and social isolation during bereavement are frequent experiences, revealing that support strategies for bereaved relatives should be developed after the loss of a loved one in the ICU.

Keywords: Bereavement research, End-of-life, Family experience, Qualitative study

Introduction

Over the last two decades, research has shown the potential impacts of the end-of-life care experience on bereaved relatives' psychological well-being, such as symptoms of prolonged grief, posttraumatic stress, anxiety and depression [1–5]. To understand their psychological well-being, bereaved relatives are more and more solicited to participate in research projects. Recent research set in the pediatric intensive care unit [6], as well as other studies based on bereaved parents [7, 8], show that participation in research projects is not harmful and may even be helpful. However, the research that is evaluated in all these studies is qualitative research, i.e. participation in a semi-structured interview occurring 12–24 months after the death.

Recent research set in the adult intensive care context has used telephone follow-up calls to complete questionnaires, and not qualitative interviews, to evaluate bereaved relatives' symptoms [1–5]. Some have contacted the bereaved relatives as early as 1 month after the patient's death [2, 5, 9]. Interestingly, responses rates are very high, varying 78–90% at 1 month [2, 5, 9] and 59–76% at 6 months [2, 5]. This research approach has rarely been evaluated. A previous qualitative study set in the ICU context sought to understand why family members participate in bereavement research [10] and showed that bereaved relatives express the need to say thank you to the ICU team, wish to help other bereaved family members, to share difficult emotions and to receive support and care. However, this study was based on relatives'

Take-home message

Bereavement research is overall associated with benefits for relatives. It highlights the importance of developing different support strategies for bereaved relatives following the loss of a loved-one in the ICU.

discussions with the caller and not on a homogenous data collection. Also this study did not explore negative aspects of research participation, showing the need to better understand difficulties and burdens encountered by family members and how these difficulties change over time as they evolve in their grief.

Bereavement is the period after a loss during which mourning occurs and grief is experienced. Kubler-Ross described the five stages of grief [11]: (1) denial and isolation; (2) anger; (3) bargaining; (4) depression; (5) acceptance. Even if people who are grieving do not necessarily go through these five stages, each of them mobilizes specific emotions in connection with the fifth stage, i.e. acceptance of the loss. It is therefore interesting to bare these stages in mind when studying participation in bereavement research over a 6- or 12-month period as timing of the call and the caller's behavior during the interview at specific time points can influence the experience of the call.

In this study, we aimed to explore bereaved relatives' experience of a specific form of research participation, i.e. telephone follow-up calls to complete quantitative questionnaires—an approach frequently used in the ICU

context, but rarely evaluated: how do relatives experience the timing of the calls, what are the potential benefits and downfalls of the calls, what is their emotional experience, what are their needs? By specifically exploring these key areas of research participation, we hope to provide guidance both for bereavement researchers using telephone calls (who can call, when etc.) and for clinicians who wish to develop telephone support for bereaved relatives.

Methods

This study is part of the larger prospective, observational, multicenter ARREVE study conducted in 43 French ICUs (in 20 university and 23 non-university hospitals) from February 2013 through April 2014 [12]. The purpose of the ARREVE study was to compare immediate extubation versus terminal weaning regarding the long-term presence in relatives of PTSD-related symptoms, complicated grief, and symptoms of anxiety and depression. Study methodology was described in a previous publication [12]. The study was approved by the ethics committee of the French Intensive Care Society (FICS-SRLF) (CE SRLF 12-396).

Subjects

Critically ill adults (older than 18 years) with a decision to withdraw invasive mechanical ventilation, and the main adult relative of each, were enrolled in the study. Consent to the study was obtained from the relatives after the decision to withdraw mechanical ventilation, but before its implementation. One relative was included per patient, the closest relative among those actively involved in exchanges with the ICU team, as identified by the ICU physicians. Participating relatives were informed that the clinical data of the patients would be collected and were asked for consent to a phone interview by a psychologist 3, 6, and 12 months after the death during which the following tools were completed: Impact of Events Scale-Revised (IES-R) at 3 and 12 months; Hospital Anxiety and Depression Scale (HADS) at 3, 6 and 12 months; Inventory of Complicated Grief (ICG) at 6 and 12 months. Responses to the open-ended questions are analyzed in the study.

Procedure

Psychologists were trained to position themselves as researchers, their primary aim being to help relatives complete the questionnaires. However, when appropriate, the psychologists were also asked to actively listen to relatives' emotions, express empathy and, when necessary, guide them towards counseling support. At the end of the 12-month call, the psychologist asked each relative if they would complete a written questionnaire

(Supplemental doc 1) about their experience of research participation. For those who accepted, the questionnaire was sent by post and included a stamped envelope for the return of the completed questionnaire.

The questionnaire comprised ten questions—each question was composed of a Likert-type scale and an open-ended question so that the respondent could complete the answer with their own words or thoughts. Themes included emotional difficulties, memories, timing, organization and potential benefits and downsides of the follow-up calls as well as support needs during bereavement.

Analysis

Quantitative

The analysis of the Likert-type scale data was performed using descriptive statistics including the median for central tendency and frequencies for variability.

Qualitative

Open-ended questions were analyzed using thematic analysis, a method for identifying, analyzing and reporting patterns (themes) within data, as described in previous studies undertaken in the ICU setting [10, 13]. Data analysis was performed by AL, research psychologist, and NKB, sociologist, both having extensive experience in qualitative research. To facilitate coding, the researchers used Nvivo 10 software, a tool that facilitates data organization [14]. They began by reading the verbatim to identify the salient points and note down the themes. The entire process was carried out individually. The researchers then met to harmonize their findings, enabling them to jointly create meaning. The objective was to understand the relationship between the sub-themes, compare analyses and select elements illustrating these themes. Findings from this process are reported as descriptive information and a sample of quotes was selected to represent the themes.

Results

Among the 311 relatives who completed the 12-month call, 175 (56.3%) sent the questionnaire back. Analysis is based on these questionnaires. Table 1 describes the characteristics of the 175 relatives who completed the questionnaire vs those who didn't. In both groups, respondents were more often women and professionally active. A significant difference appears between the two groups concerning the relationship to the patient: compared to those who didn't complete the questionnaire, relatives who did were more often the spouse/partners of the patients (24.4% vs 43.2%) and less often the adult children (39.6% vs 51.7%).

Table 1 Characteristics of relatives who completed the questionnaire vs those did not complete the questionnaire after the 12-month follow-up call

Type	Relatives who completed the questionnaire (n = 164) Missing data for 11 respondents	Relatives who didn't completed the questionnaire (n = 147)	p value	
Age			0.2251	
	Mean ± SD	55.1 ± 12.8	53.3 ± 13.8	–
Gender			0.0124	
Female	n (%)	128 (78)	96 (65.3)	–
Relationship to patient			0.0056	
Grown child	n (%)	65 (39.6)	76 (51.7)	–
Spouse/partner	n (%)	71 (43.2)	36 (24.4)	–
Parent	n (%)	4 (2.4)	6 (4)	–
Other	n (%)	24 (14.6)	29 (19.7)	–
Professional occupation			0.053	
Working	n (%)	88 (53.6)	81 (55.1)	–
Unemployed	n (%)	7 (4.2)	5 (3.4)	–
Retired	n (%)	61 (37.2)	43 (29.2)	–
Other	n (%)	8 (4.8)	18 (12.2)	–
Level of schooling			0.0655	
No degree	n (%)	24 (14.6)	23 (15.6)	–
Completed middle school	n (%)	39 (23.7)	50 (34)	–
Graduated from high school	n (%)	28 (17)	18 (12.2)	–
Bachelor's degree	n (%)	25 (15.2)	29 (19.7)	–
Graduate degree	n (%)	48 (29.2)	27 (18.3)	–
Religious beliefs			0.1331	
No religion	n (%)	55 (33.5)	36 (24.4)	–
Catholic	n (%)	101 (61.5)	97 (65.9)	–
Jewish	n (%)	1 (0.6)	0 (0)	–
Muslim	n (%)	2 (1.2)	3 (2)	–
Other beliefs	n (%)	5 (3)	11 (7.4)	–
Presence at time of patient's death in the ICU			0.6917	
Yes	n (%)	98 (59.7)	84 (57.5)	–

Table 2 presents the quantitative results of the questionnaire (Likert-type scale) and shows that the follow-up research strategy was adapted: respondents describe the three calls as very easy to schedule (7 [6; 7]) and neither too long or too short (4 [4; 5]). Over 74% believe that our approach that included three calls was adapted. Respondents experience research participation as beneficial both for themselves (6 [5; 7]) and for other family members (6 [5; 7]). Interestingly, they also express that out of a research context, a follow-up call after the loss of a loved-one in the ICU would be highly beneficial (7 [5; 7]), specifically between 3 and 6 months (43.2% and 30.8% respectively).

We derived three themes from the thematic analysis of the open-ended questions: (1) struggling—emotional and psychological impacts of the research calls: difficult experiences; (2) resilience—“As time goes by...”: positive experience of research participation;

(3) recognition—research calls: compensating for the absence of support (Fig. 1).

Theme 1: struggling—emotional and psychological impacts of the research calls: difficult experiences

Two frequent sub-themes

Reactivation of the emotional distress associated with loss **Research calls awakened memories associated with the loss and hospitalization of a loved-one: “All the bad moments of the end-of-life return to the surface, which is very hard”.** Reactivations were also linked to the vision of their loved-one on life support and of the dying process: “The questions made me visualize the images, hear the voices, feel the emotions; it was very hard to bear.” This experience was associated with intense feelings of distress: “It really stirred things up right after the call (especially the 1st call); it felt like a boomerang of these past 3 months,

Table 2 Responses to the quantitative questions

For questions 1–5 and 7–9, respondents were asked to answer using a Likert-type scale ranging from 1 to 7	N = 175
1. Overall, participating in the study has been for you	
Emotionally very difficult → not emotionally difficult at all	4 [3; 6]
2. What sort of memories did the follow-up calls arouse	
Unpleasant memories → very pleasant memories	4 [3; 4]
3. The series of follow-up calls were experienced by you as	
More and more difficult → less and less difficult	5 [5; 6]
4. On a practical level, these follow-up calls were	
Very difficult to schedule → very easy to schedule	7 [6; 7]
5. For you, these follow-calls were	
Much too long → not long enough	4 [4; 5]
6. Would you say that	
One call would have been sufficient to express my feelings	13 (7.6%)
Two calls would have been sufficient	9 (5.3%)
Three was the right number of calls	127 (74.7%)
You would have appreciated more calls	21 (12.4%)
7. Overall, participating in the study was for you	
Not beneficial at all → highly beneficial	6 [5; 7]
8. Overall, you believe this study will be	
Not helpful for other family members → very helpful for other family members	6 [5; 7]
9. Out of a research context, do you think that a follow-up call (to check on relatives, to answer questions) would be beneficial for bereaved relatives	
Not beneficial at all → highly beneficial	7 [5; 7]
10. In your opinion, when would be the best timing for such a follow-up call?	
Approximately 3 months after the loss	73 (43.2%)
Approximately 6 months after the loss	52 (30.8%)
Approximately 12 months after the loss	17 (10.1%)
Other	27 (15.9%)

Median [Q1; Q3] for the quantitative variables; *n* (%) for the qualitative variables

even though I had not been necessarily conscious of my feelings”. However, an abreaction phenomenon can be detected in some relatives. They note that by reliving their experience, however hard, they are able to release repressed emotions, thus becoming aware of traumatic aspects of the event: “Of course these discussions revived a lot of painful memories but they helped me understand some of my emotions and to put words onto my grief”.

The first call, the most difficult Three months after the patient’s death, many say that they are struggling with the loss and how much they cried during and after this call. Crying is a way to unload accumulated tension and to express sadness: “The first call was very close to my mother’s death so I was totally immersed in emotion. I cried a lot after the call”. In spite of heightened emotional distress, the call can

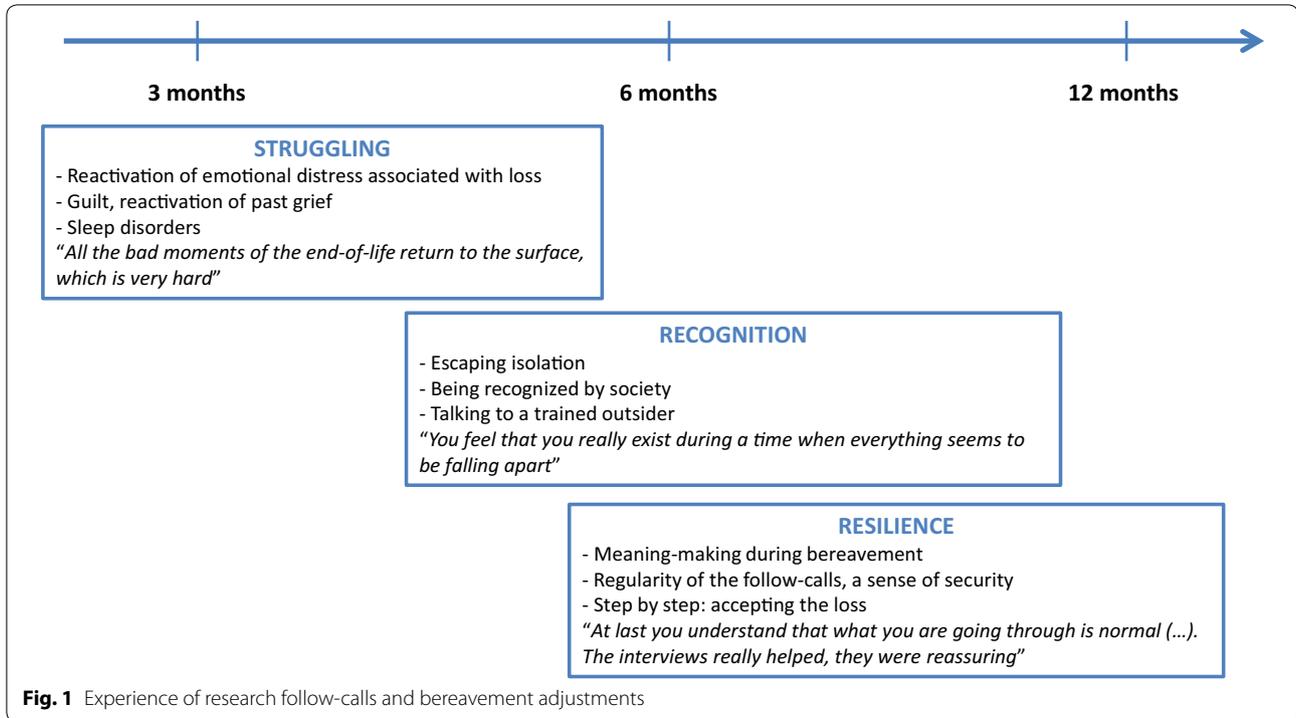
however also provide a sense of emotional release that allowed them to “get things off their chest”.

Three other less frequent sub-themes

Feelings of guilt associated with end-of-life decisions were expressed by some relatives: “Remembering that I had to make the decision and say ‘yes, now you can unplug the machine’, since there was no longer any hope.”

Reactivation of past grief was also experienced by some participants: “Through the interviews I somewhat relived family bereavement experienced in the past.”

Sleep disorders after the interview were exceptionally reported: “Some memories I thought forgotten actually re-emerged and took me back to the critical care period and disturbed my sleep for several weeks.”



Theme 2: resilience—"As time goes by...": positive experience of research participation

Meaning-making during bereavement

In their answers to the questions, relatives indicated that the calls permit continuity while death is a breaking point. First, they were an opportunity to bring up memories of the deceased: "Emotion and sadness but so proud of having had a husband like C., he was exceptional and I'm happy to be able to say so". Second, discussing the patient's hospitalization and/or death during the follow-up calls was perceived as a way to better understand what happened in the ICU and to maintain a connection with the ICU team: "If there hadn't been this study, after the death, I wouldn't have had any contact with the ICU, no phone-call, nothing, it's a shame. So I think these calls were necessary and beneficial".

Regularity

The regular telephone calls were experienced as a means to come to grips with bereavement. First, they were a means to give meaning to their situation and to the changes it carries: "It helped me realize that I had accepted my father's death and that I could now think of him with pleasure". Second, the calls enabled the relatives to position themselves with regards to others, thus creating what they described as "landmarks": "At last you understand that what you are going through is normal, your emotions, your memories. The interviews really

helped, they were reassuring". Last, relatives declared that the repeated calls were a means to connect the past, the present and a possible future: "The calls were beneficial as they were a way of connecting the "before and after" that didn't really seem possible to connect at first".

Step by step: accepting the loss

The second call still remained emotionally difficult, although less than the first. Relatives indicated that at this time they had started to accept the loss: "The second call was easier, even soothing, as I could talk about my mother using the past tense". At this stage, acknowledging the separation was perceived as possible: "Luckily, with time, the pain of separation lessens; the second call wasn't as difficult".

Relatives also noted that after 6 months have passed since the death, they were starting to feel less helpless and wanted to envisage the future: "The calls were less and less difficult as, with time, you accept, or at least you try to accept, the loss of your loved-one, even if it still hurts, you have to move forward, for yourself, your family, your children and for the deceased".

In fact relatives noted that they were conscious of the benefits of these follow-up research calls: "At the end of each call I felt calmer. Talking to someone does help you see where you stand".

The last call was unanimously experienced as the most positive and sometimes even as the most soothing.

Relatives indicated that at this stage they had accepted the loss, were more focused on the future and felt more confident. They noted that the last call was an opportunity to analyze their grieving process: “The first two calls were emotionally very difficult but during the last call, I managed to express myself positively and see the good sides of his hospital stay”. Relatives indicated that talking about their experiences helped them realize where they stood and what they wanted/needed.

However, they also indicated that realizing that it was the last call could be difficult: “I actually felt nostalgic during the last call because during these calls I would think about my father, I would remember him, I still had a connection with him”.

Theme 3: recognition—research calls: compensating for the absence of support

The follow-calls, a means to escape isolation

Relatives experienced the follow-up calls as a means to not feel abandoned and to escape isolation. This theme was recurrent in answers to questions 7, 8 and 9: “I accepted this study because it was a way for me not to drown in my solitude and in my pain. You helped me keep my head above water, like a lifeline”.

A social dimension: being recognized by society

The social dimension of the calls was also highlighted by relatives. Being contacted by an outsider (neither family nor ICU clinicians) can generate a sense of uniqueness and of being recognized by society: “It should be obligatory [to be called], you feel that you really exist during a time when everything seems to be falling apart. Thank you so much”.

The concept of solidarity appeared throughout the relatives’ answers, showing the high risk of isolation and vulnerability: “I felt less alone and abandoned because there was actually someone out there who wanted to know how I was doing—that’s a real boost to the moral”; “As she asked questions that resonated with my experience, I felt better. I felt that I was part of a whole, something bigger, and that I wasn’t alone”.

In return for this attention, relatives noted that they were happy to participate in the study, especially if this could lead to improving knowledge and family experience: “It helped me to talk about that difficult moment and also maybe it will help other families in pain”.

Talking to an experienced and trained outsider

Relatives also indicated that these calls were a unique opportunity to express themselves, notably because they were a chance to talk to a third party: “Even within a

family there are some subjects you can’t talk about, revive bad memories, with someone from the outside it’s much easier”. The psychologist offered “a space” in which the bereaved could express themselves openly and deposit emotions and feelings that they were still finding difficult to cope with alone: “It was always the same person who called me, she was patient and kind. As I could trust her, my sorrow was less violent”.

Despite the interview framework imposed by the questionnaires, the bereaved relatives felt that the psychologist left room for the singular expression of emotions: “It’s very complicated to fit into a box something which cannot, but the psychologist made it possible to go beyond the limitations imposed by boxes.”

The psychologist was perceived as someone who understands the ICU and who was therefore able to hear and answer their questions: “Being able to talk with someone who knows these moments helped sooth the pain and stress. It allowed me to release the anger I felt toward the doctors.”

Discussion

In this study we showed that research participation in the form of telephone follow-up calls to complete various quantitative tools was overall a positive experience for family members. Although some emotional difficulties must be acknowledged by researchers, our study showed that these research calls are interesting for participants who described them as therapeutic experiences that can sometimes make up for the absence of bereavement support. The emotional difficulties encountered are described as “necessary” in that they are an opportunity for relatives to express themselves, remember their loved-one and discuss their experience in the ICU [15].

This research is specific in that bereaved participants were (1) called three times by the same person (a psychologist), thus enabling a reliable follow-up; (2) asked to complete quantitative tools but with the help of a psychologist permitting to go further than simple completion toward deeper discussions. As this research was conducted over 9 months, relationships developed and participants often awaited the calls. The border between research and therapy is difficult to analyze [16]. However, it is important to insist on the difference between “therapy” (the treatment of psychological disorders by psychological means) and “therapeutic experiences” [17] that are moments that help the person to evolve and change (but not an intentional treatment). Research participation can contain “therapeutic experiences” and, as such, researchers must be trained and capable of active listening and expressing empathy. In some cases, bereaved relatives’ participation may be more a desire for follow-up care,

rather than actual research participation and we must acknowledge this risk. Researchers must be able to evolve with participants over time [18], respecting the temporality of grief: stages of grief will affect relatives' emotions and experience of the research calls.

These qualities enable to establish a trusting relationship between the interviewer and the bereaved relative. However, what seems important to the latter is not only being able to talk about his/her experience, but also finding a space in which his/her words and feelings can be received and contained. The interviewer is perceived as a recipient of painful emotions and a help to reflect upon and bear what they are going through. The research follow-up calls enable resilience: the ability to be resilient mainly depends on the existence of support in one's environment [19]. This support is based on the ability to receive bereaved persons' emotions and to transform them into elements that make sense [20], as well as on the ability to put the bereavement experience into words. It is thus essential to encourage the expression of questions, remarks, and doubts, as long as the interviewer is knowledgeable about ICU experiences and families' trajectories in this context. The interviewer's posture is thus essential: finding a balance between being emotionally close and providing an external perspective on the bereaved person's experience. Our study highlights the importance of interviewers' advanced training both in qualitative approaches and in bereavement support so as to be able to correctly support and actively listen to the potentially vulnerable bereaved relative.

Providing a regular follow-up as part of the data recovery strategy presents several biases: (1) the bereaved may feel they are being helped and this help, if experienced as beneficial, may affect how they answer the different quantitative questionnaires. Would a relative completing written documents (and receiving no calls) complete the questionnaires in the same way as those who are accompanied by a psychologist? (2) Calls during which the bereaved relative describes his/her loss and its impact may have a therapeutic effect, thereby influencing the very process we are studying [16].

Interestingly, as said above, the incentive to complete the three follow-up calls may be a desire for support rather than active participation in the research project: we have seen that the follow-up calls are experienced as a form of support, an opportunity to express themselves and to share difficult emotions as well as a means to not feel abandoned [10]. These results highlight the fact that this support does not exist and family members make use of these research follow-up calls for lack of anything better. Clearly they need to be able to talk, to tell their story [21] and to give meaning to their experience [22] but our society does not propose easy

access to bereavement support. As shown in Fig. 1, the process experienced by the relatives starts with a stage of emotional struggle, is followed by a stage of acceptance during which outside support plays an important role and ends with resilience. It is important to define who should be involved in bereavement support and what type of support should be offered [23, 24]. As many families appreciate contact via the telephone, the possibility of developing a helpline specific to bereaved relatives after the loss of a loved-one in the ICU should seriously be considered.

Last, our results also highlight a specific grieving experience that occurs after the loss of a loved-one in the ICU that may be of particular interest for ICU clinicians who wish to improve their practices [25]. Indeed, while the reactivation of distress and guilt following interviews is a normal manifestation of the grieving process, these feelings are strongly marked by their experiences during visits to their loved-one. Several months after the loss, bereaved relatives still have in mind very clear images of the patient in the ICU. Some also express guilt marked by a sense of responsibility in end-of-life decision-making. This is consistent with a study by Cunningham et al. [26], which found that families are not always sufficiently informed and supported to shoulder the role of highlighting patients' wishes and values.

Our study presents several limitations. First, it was conducted in France where bereavement support is rare and this may be different in other countries. Second, relatives who completed this study were those who participated in the study and received the three follow-up calls: understanding why some relatives choose not to participate or decide to stop participation should be developed. Also a better description of those who refused to complete the questionnaire would be interesting: maybe their experience of the follow-up calls was less positive. However, access to these individuals is problematic as one must fully respect the decision of a bereaved person not to participate in a research project. Third, we must take into account the time that elapsed between the telephone interviews (3, 6 and 12 months) and the moment when the bereaved individuals completed this questionnaire (after the 12-month call). They possibly relied primarily on their most recent feelings as drawing on their past experiences may have been difficult.

Conclusion

This study adds to the existing literature on bereavement research by confirming that early contact with bereaved relatives is possible and is overall associated with benefits, on condition that the follow-up research team has followed adequate training. Our study also highlights

bereaved relatives' difficulties, both during research calls and more generally during bereavement (the two being intertwined), as well as lack of support. It is thus necessary to develop different support strategies for bereaved relatives after the loss of a loved one in the ICU, maybe in the form of a helpline that would offer bereaved relatives the opportunity to be listened to, understood and supported.

Electronic supplementary material

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Compliance with ethical standards

Conflicts of interest

The authors declare that they have no conflict of interest.

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